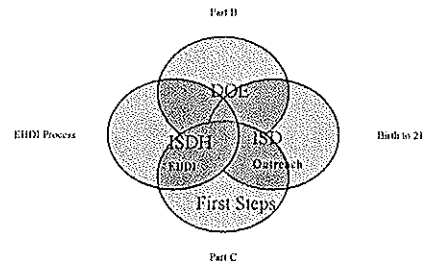


# Indiana's Early Hearing Detection and Intervention (EHDI) Program

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## Indiana State Agencies Serving Deaf and Hard of Hearing Children and their Families



## EHDI

- What do you know about Indiana's EHDI Program?
- Have you seen a difference in children who were identified early because of UNHS?
- What differences do have you seen in parents of our Indiana babies in the past 8 years since EHDI was implemented?

## Presentation Overview

- Incidence of Hearing Loss
- Trends across the Country
- History of Early Hearing Detection and Identification (EHDI)
- EHDI Goal Areas
- Numbers, numbers, numbers!
- Keeping Track of children
- Family Support



## Incidence of Hearing Loss

- 1 in 300 babies is born with a hearing loss (3 per 1,000)
- Most babies are screened at birth
- As a result, babies are now being fitted with hearing aids as early as 4 weeks of age
- An additional 6 children per 1,000 will develop permanent hearing loss by school age
- Consequently, hearing should be monitored throughout early childhood

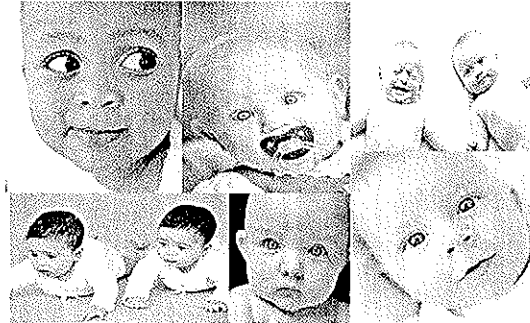
## Trends Across the Country

- Success in screening the majority of newborns by one month of age (improving from 5% in 1993 to 95% in 2006, CDC)
- More effective technology-Earlier age of identification
- Continued shortage of audiologists trained in pediatric procedures
- Shortage of educators and SLPs trained to work with "today's" deaf and hard of hearing children
- Infants vs. toddlers, multiple conditions

## Trends Across the Country

- Increasing numbers of parents choosing cochlear implantation
- Parent empowerment, parent advocacy, parents as partners with professionals
- Shift in the Culture (94% of children are born to parents with normal hearing)
- Mobilizations of forces at the federal level

## It's a Brave New World.....



## Why is early identification of hearing loss important?

- Many children have hearing loss (3 per 1000 infants; another 6 per 1000 children acquire hearing loss during early childhood)
- Any degree of hearing loss can significantly impact a child's speech and language development
- Hearing loss impacts a child's life and may add information about the child—who is he is, the way that he will go.....
- Early identification and appropriate intervention make a difference!



## History of EHDI

- Prior to 1990-Focus on high risk babies  
Average age of identification: 2 years;4 mos
- *Healthy People 2000*-Decrease age of identification to below age 12 months
- *Healthy People 2010*-Focus on 1-3-6;  
1-Screen, 3-Identification 6-Intervention



## EHDI in Indiana



- PL91-1999-"every infant receive a physiologic hearing screening at the earliest feasible time for the detection of hearing loss."
- Religious refusal=only acceptable reason to refuse screening
- All birthing facilities were to be in compliance with the law by July 1, 2000.

## National Numbers – 2006 Data

- Incidence of Hearing Loss: 1.2 per 1,000 screened babies
- % Referred to Part C EI: 87.4%
- % Enrolled in Part C EI: 52.5%
- % Receiving Non-Part C EI: 8.2%
- % Receiving No EI Services: 39.3%
- % LFU/LTD: 33.9%

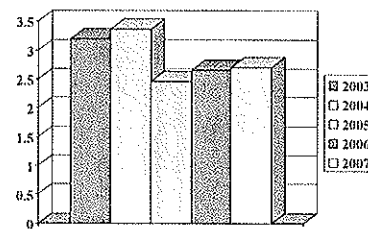
## National Numbers vs Indiana Numbers – 2006 & 2007 Data

	National	IN 06	IN 07
% screened	92.2%	97.8%	98.1 %
% not passing	2.1%	1.9%	1.9%
% normal hearing	29.9%	73%	65%
% hearing loss	5.8%	7%	7.5%
% lost to follow up	46.3%	15%	20.8%

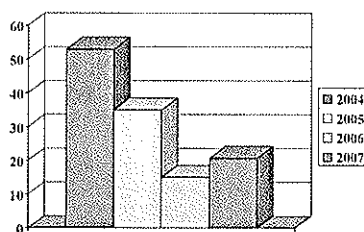
## More and more babies

- 75 Babies were identified with hearing loss in 2003 (.76 per 1000 births)
- 101 Babies were identified with hearing loss in 2004 (1.03 per 1000 births)
- 108 Babies were identified with hearing loss in 2005 (1.1 per 1000 births)
- 127 Babies were identified with hearing loss in 2006 (1.3 per 1000 births)
- 132 Babies were identified with hearing loss in 2007 (1.4 per 1000 births)

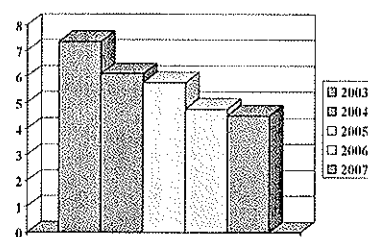
## Average Age of Evaluation in Months



## Loss to Follow-Up/Documentation



## Average Age of Diagnosis in Months



## EHDI in Indiana Components of the Program

- 1-3-6
- Medical Home
- Family Support
- Interagency Cooperation



## EHDI in Indiana: Partners and Stakeholders

- 105 birthing facilities
- Physicians and nurses, local health depts
- Early intervention direct service providers
- State and private entities and organizations
- Indiana State Dept of Health EHDI Advisory Committee
- THE BABIES AND THEIR PARENTS!



## EHDI in Indiana Staff working at EHDI

State Coordinator  
UNHS Nurse Consultant  
EARS Follow-Up Coordinator  
Parent Consultant  
Regional Audiology Consultants



## The EHDI Alert Response System (EARS)

EARS is a web-based application that:

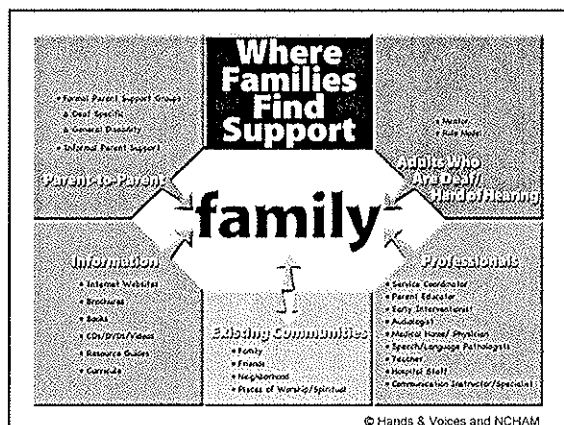
- allows hospitals and audiologists to enter information directly into a data store;
- allows Indiana EHDI staff almost instantaneous access
- generates alerts and informs the appropriate staff member re: the next follow-up action.

## Indiana EHDI and Support of the Family

- Role of the EHDI Parent Consultant
- The Touchstone Approach
- Connecting families with resources
- Working with other state and community agencies
- Providing continuing education
- New program-Guide By Your Side!

## EHDI encourages families to:

- Work in partnership with professionals as part of a team
- Know their rights regarding service provision, financial support, reimbursement, etc.
- Talk with other parents
- Understand what information should be provided at appointments and meetings



## EHDI - First Steps Help Kit

- Tool for consistent provision of services to families across the state
- Step-by-step procedures for UNHS referrals
  - Referral process from EHDI to First Steps
  - Follow-up processes based on diagnostic findings

## First Steps Referrals include:

- Babies who "did not pass" UNHS in one or both ears
- Babies who passed UNHS, but had one or more risk factors for late onset hearing loss
- Babies who could not be screened due to ear malformations

## Overview of Referral Process

- Hospital/birthing facility
  - reports all hearing screening referrals to ISDH
  - refers babies not passing and those with risk factors to the appropriate SPOE
- ISDH sends re-referral to the SPOE via secured email to ensure that children are not lost to follow-up

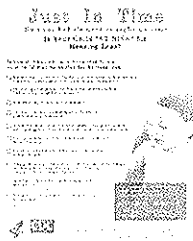
## Overview of Audiological Follow-up

- First Steps assists family in choosing a provider and scheduling diagnostic testing (Level 1 Audiology Facility list)
- Reciprocal release should be signed
- Physician Health Summary form obtained and sent to audiologist

## Level 1 Audiology Providers

- Identified based on survey of audiologists in or bordering Indiana
- Level of facility determined based on use of **specialized equipment** necessary for accurately assessing infants' hearing
- Remember, Level 1 facilities may not be a First Steps Provider and not all First Steps Providers are Level 1 facilities

## A Word about Risk Factors



State-recommended First Steps follow-up:

- Family History
- In utero infection
- Hyperbilirubinemia (if exchange transfusion)
- Ear malformation that prohibits screening

## Screening Status: Did Not Pass

- Baby is referred for follow-up audiological testing, which should be scheduled as soon as possible, but no later than 3 months of age
- Baby's hearing should be evaluated until a diagnosis is obtained.
- Approximately 10% of referred babies will have a hearing loss

## Screening Status: Passed UNHS with Risk Factors

- At 7 months of age ISDH sends a reminder letter to families regarding need for follow-up hearing evaluation at 9-12 months of age
- Receive follow-up at 9-12 months of age and then as recommended by the audiologist

## Diagnostic Status: Normal Hearing (with or without Risk Factors)

- Encourage the family to follow audiologist's recommendations for retesting
- Provide family with Language and Hearing Developmental Milestones and encourage family to discuss any future concerns regarding hearing or development with primary care physician

## Diagnostic Status: Hearing Loss

- Schedule ED team evaluation as required
- IC will schedule an IFSP meeting according to FS timelines
- Include managing audiologist in the IFSP meeting (written input can be provided by audiologist if they cannot attend in person)
- Inform audiologist when services can be provided (send copy of IFSP)

## Diagnostic Status: Hearing Loss



- Make sure family has received copy of Family Resource Guide
- If not, have family contact EHD1 Program at 1-888-815-0006 for assistance
- Audiologist will complete Request for Authorization for Audiology Services form

### Authorizing Payment for Hearing Aid Related Services

- Fax Request for Authorization for Audiology Services to SC
  - When authorizations entered in system, audiologist can dispense equipment and provide services
  - Hearing aids must be ordered with loss/damage warranties coverage through child's 3<sup>rd</sup> birthday
- An otologic evaluation by an otolaryngologist (ENT physician) must be completed prior to the fitting of hearing aids
  - *This is not a FS responsibility but is typically recommended by the audiologist and arranged through the infant's primary care physician.*
- BAHA and Cochlear implants are not a covered service through FS

### Authorizing Payment for Hearing Aid Related Services

- Hearing aids or hearing aids digital - monaural or binaural
- Hearing aid evaluation/examination and selection - monaural or binaural
- Dispensing fee – monaural or binaural
- Hearing service miscellaneous ( earmolds)
- Hearing aid management
- Hearing aid batteries
- Hearing aid supplies – pediatric hearing aid kit

### Diagnostic Status: Hearing Loss and the IFSP

- Hearing aid evaluation, fitting, and follow-up
- Follow-up hearing testing to further define hearing loss and to monitor hearing levels.
- Family education to discuss results of evaluation, care and use of hearing aids, encourage adjustment to hearing aids, wearing schedule, implications of hearing loss, etc.

### Ongoing Audiological Services and the IFSP



- Examples of IFSP strategies:
  - Further define unaided hearing thresholds
  - Verify and adjust hearing aid settings as hearing loss is further defined
  - Monitor performance with hearing aids
  - Counsel families on the care and use of hearing aids and monitor communication development.

REFER TO HELP KIT FOR EXAMPLES

### REMEMBER THE AUDIOLOGIST AT IFSP TIME!

- Several months before expiration of active IFSP, inform and include audiologist in any IFSP review so they can provide updates and provide a new Audiology PA request
- The Request for Authorization for Audiology Services form should include requests for services and equipment (i.e. batteries, earmolds) as necessary.

### Parents FAQs: Talking Points

When a family doesn't understand why follow-up is necessary, explain that:

- Rule out any amount of hearing loss in one or both ears
- Diagnostic testing clarifies how your baby is hearing
- Even if your baby responds to sounds, a mild or moderate hearing loss or a hearing loss in one ear may still be present
- Follow-up testing is safe and painless
- Any degree of hearing loss can potentially impact speech and language development

## Parents FAQs: Talking Points

When a baby has risk factors and it's time for follow-up:

- A baby can develop hearing loss even after passing UNHS
- Your baby was identified as having a risk factor for hearing loss and needs to be checked again
- Hearing loss is invisible and you can't be sure without further testing that your baby's hearing is normal
- Speech/language and hearing milestones should be closely watched

## Parents FAQs: Talking Points

For families whose infant has been diagnosed with a hearing loss:

- Acknowledge the parent's feelings. A sincere, caring attitude, even if you don't have all the answers is noticed and appreciated.
- Consider the parents feelings as well as the specific needs of the child
- If families have questions that you cannot answer, have them contact the ISDH EHDl Coordinator or Parent Consultant

## Parents FAQs: Talking Points

For families whose infant has been diagnosed with a hearing loss:

- Assist the families in obtaining the intervention that they have chosen for their baby
- Give them information about parent support groups in your area. Parents want and need the support of other parents
- Encourage family to look at the Family Resource Guide (provided by audiologist and EHDl) and recommended websites for information

## Family Support Services

- Provide family support information to families including how to connect to the SKI\*HI Program and family support organizations (Indiana Hands & Voices, HEAR Indiana, American Society for Deaf Children)
- If family chooses to pursue SKI\*HI, include SKI\*HI Parent Advising on the IFSP, Section 9 (Related Services) and notify Outreach Services for Deaf/Hard of Hearing regarding the referral
- Refer to SKI HI kit provided by Outreach Services at Indiana School for the Deaf for specific procedures
- Additional new programming on its way!

## If Family chooses not to Pursue First Steps' Services



- Encourage the family to schedule a diagnostic assessment with their chosen audiology provider
- Help them locate an audiologist who is equipped and experienced in evaluation of infants. (Level 1 Facility)
- Answer any questions families may have and/or refer or redirect them to the EHDl Program – 1-888-815-0006

## If Families Choose Not To Pursue First Steps' Services

- Refer to Children's Special Healthcare Services (CSHCS) can provide funding for diagnostic testing if the family meets enrollment criteria
- CSHCS phone number:  
1-800-475-1355
- Investigate personal insurance or Medicaid eligibility.



**Coming Soon to a  
Location Near You!**



- EHDI-First Steps Help Kits
- Even earlier identification, diagnosis and intervention
- Indiana Guide By Your Side program
- More positive outcomes for CHILDREN!!